

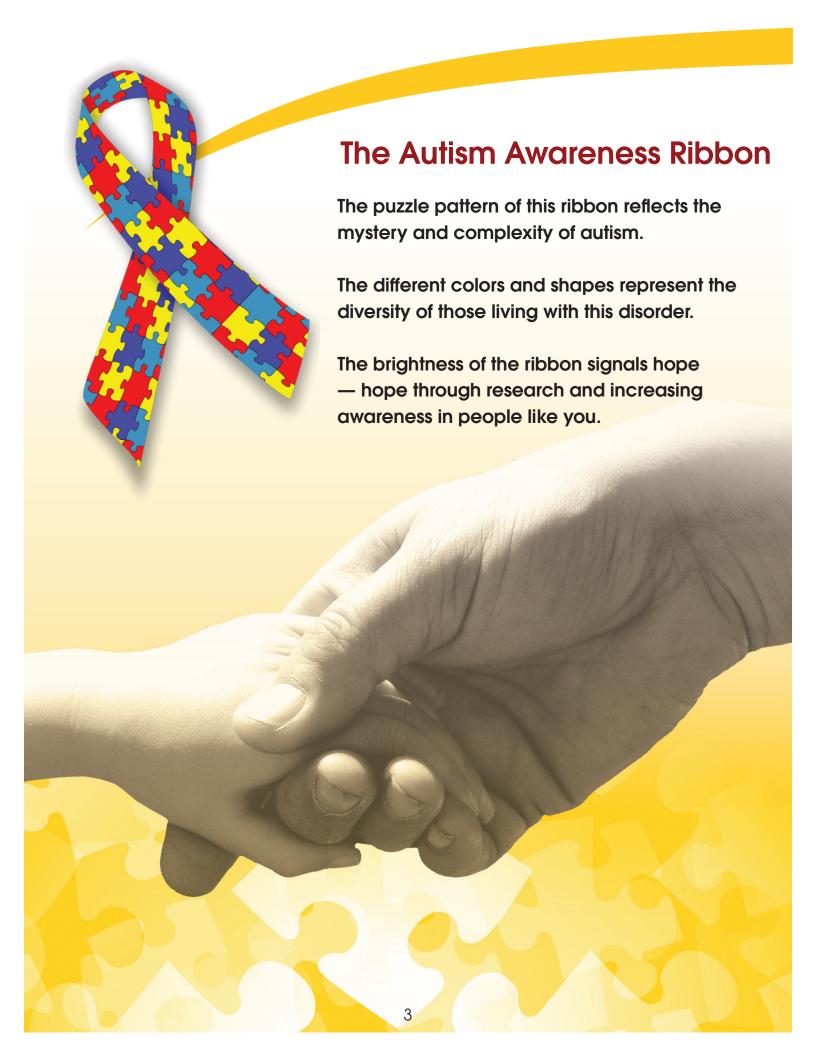
Autism Spectrum Disorders Resource Booklet

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Disclaimer

The content within this booklet is for informational purposes only. It is not intended to be a substitute for professional medical advice. Families are encouraged to discuss the information in this booklet with their child's doctor or other health-care providers.



Specialty Health Services

For nearly all children on the autism spectrum, evaluation by an experienced team of professionals is necessary for an accurate diagnosis and optimal treatment planning. Families are an essential partner to the team, as they are the principle caregiver and the center of strength and support for the child. The following link provides access to a resource that offers guidelines for the care of children with an autism spectrum disorder: www.ohsu.edu/cdrc/medicalhome/docs/autism.pdf.

Multidisciplinary Clinics

For more information about Children's Special Health Services (CSHS) clinics, review the following link: www.ndhealth.gov/cshs/docs/clinic-schedule.pdf.

Great Plains Interdisciplinary Autism Diagnostic Clinic (GPIC)

Children's Special Health Services (CSHS) supports autism clinics in Jamestown and Minot. The purpose of these clinics is to provide diagnostic services, including screening and follow-up services, to families of referred children. Referrals most often are made by local providers, but can also be made by families. Two children are screened at each clinic in an arena-style format. In this environment, the interdisciplinary team works in one room with the family present to perform screening and provide recommendations to the family. The sites for the autism clinics are listed below:

Jamestown Minot

Anne Carlsen Center Minot State University Campus 701 3rd St. N.W. 500 University Ave. West Jamestown, ND 58401 Minot, ND 58707

For more information, contact GPIC's Family Support Specialist at 800.233.1737.

Sanford Health's Pediatric Developmental Evaluation Clinic (Fargo)

This clinic is for any child (age 6 months and older) for whom a full developmental assessment is warranted. In the clinic, each child is evaluated fully by a speech therapist, occupational therapist, pediatrician and dietician. The families also are seen by a medical social worker and a registered nurse. Diagnosis of an autism spectrum disorder facilitates at least one follow-up visit with the child and family. These visits are intended to monitor the child's progress and ensure that appropriate services are in place for the child and family. For more information, contact Sanford Health's Coordinated Treatment Center at 800.828.2901.

Altru's Developmental Assessment Clinic (Belcourt and Fort Totten)

These clinics (sponsored by a grant through CSHS) provide annual developmental assessments for high-risk children in Belcourt and Fort Totten. A team of specialists perform comprehensive evaluations to determine the need for further services. For more information, call 701.780.2477.

Altru's Pediatric Developmental Clinic (Grand Forks)

This clinic serves children who are considered to be at risk for developmental issues. Located in Altru's Main Clinic, the Pediatric Developmental Clinic integrates physical and occupational therapy screenings as well as nutrition services with the child's physician appointment. Together, the team then determines if the child has a need for additional services. For more information, call Altru Pediatrics at 701.780.6110.

Rehab Pediatric Therapies Screening Clinic with a Focus on Autism Screening

This clinic is held four times per year and features a multidisciplinary team that eliminates the need for parents to attend multiple appointments on different days. Parents and providers who have concerns regarding a child's development have access to the screening clinic at no cost. For more information, please call 701.780.1540 or 701.780.2481.

Support Autism in North Dakota (SAND)

The Support Autism in North Dakota (SAND) project is designed to improve North Dakota's infrastructure to provide comprehensive, coordinated health care and related services for children and youth with Autism Spectrum Disorders (ASD) and other developmental disabilities. For questions or more information, contact the project director at 701.858.3008.



Genetic Services

Genetic/Birth Defect Clinics are held periodically throughout the state. For clinic schedule information, call Children's Special Health Services toll-free at 800.755.2714 or contact the following:

Division of Medical Genetics

Department of Pediatrics UND School of Medicine and Health Sciences Room 5910 501 Columbia Road North STOP 9037 Grand Forks, ND 58201

Telephone: 701.777.4277 or 701.772.5301 www.med.und.nodak.edu/pediatrics/genetics

Sanford Health Medical Genetics

737 Broadway North Fargo, ND 58102

Telephone: 701.234.2362

www.north.sanfordhealth.org/medicalservices

Informed Medical Decisions

(telehealth genetic counseling services) North Dakota Contact: Marie Schuetzle, MS, CGC

Senior Genetic Counselor

Telephone: 760.230.4251

Fax: 760.203.1194

www.informedDNA.com



Therapy Providers for Autism Spectrum Disorders

Bismarck

Sanford Health Pediatric Rehabilitation 701.323.6097 www.medcenterone.com

Red Door Pediatric Therapy 701.222.3175 www.reddoorpediatric.com

St. Alexius Pediatric Therapy 701.530.5550 www.st.alexius.org

Kids Therapy Center 701.751.0384 www.thekidstherapycenter.com

Dickinson

Rehabilitation Visions 701.483.9400

Fargo

Beyond Boundaries Therapy Services 701.356.0062 www.beyondboundaries.us

Fargo-Moorhead Pediatric Therapy 701.261.4643 www.fargo-moorheadpediatrictherapy.com

Essentia Health Pediatric Therapy Services 701.364.6247 www.essentiahealth.org

Sanford Health 701.234.6500 www.north.sanfordhealth.org/medicalservices

North Dakota Autism Center 701.277.8844 www.ndautismcenter.org

Pediatric Partners 701.232.2340 www.pediatrictherapypartners.com

Grand Forks

Altru Health System Pediatric Therapy Services 701.780.2477 www.altru.org

Little Miracles, Inc. 701.772.3851 www.littlemiraclesinc.com

Hettinger

West River Health Services 701.567.4561 www.wrhs.com

Jamestown

Jamestown Hospital 701.952.4842 www.jamestownhospital.com

Minot

Trinity Health 701.857.5623 www.trinityhealth.org

Valley City

Mercy Hospital 701.845.6400 www.mercyhospitalvalleycity.org

Williston

Mercy Medical Center 701.774.7436 www.mercywilliston.org

Additional Resources

Anne Carlsen Center (ACC) offers a rich tradition of empowering individuals with disabilities and their families. Their experienced staff provides compassion, training, services and supports in homes and communities across North Dakota. On the Jamestown campus, they meet the educational, residential and therapeutic needs of children and young adults with autism, behavior disorders, medical fragility and other developmental disabilities. They also provide services in the home through customized supports for individuals from birth to age 21. In addition, through their community-based services (i.e., in-home supports and community day supports), Anne Carlsen accommodates individuals of all ages, including adults. For more information about services in the Dickinson and Bismarck locations, call 701.934.1144. www.annecenter.org

Fargo	Grand Forks	Jamestown
1323 23rd St. S.	2860 10th Ave. N.	701 3rd St. N.W.
Fargo, ND 58103	Suite 400	Jamestown, ND
701.364.2663	Grand Forks, ND 58203	701.252.3850
	701.757.4200	800.568.5175
	888.815.3770	

Autism Waiver provides services for young children from birth to age 5 who have a diagnosis of an autism spectrum disorder. The waiver will give families access to an evaluation team that can validate their child's diagnosis and serve as a resource for the family's local service providers. Other waiver services include Developmental Disabilities Program Management, parent training and support (Intervention Coordination), and In-Home supports (additional care giving to help with day-to-day activities and respite). The waiver also provides financial help with the cost of equipment, supplies and environmental modifications. Apply by contacting the Developmental Disabilities Unit at one of the regional human service centers. Contact information is online at www.nd.gov/dhs/locations/regionalhsc.



Birth to Three Early Intervention is a support and service program designed to help families with children from birth to age 3, with disabilities and/or developmental delays. The goal of this program is to improve a child's development and to increase involvement in family and community life. By partnering with families, ND Early Intervention provides them with the tools and support they need to help their child be successful. Qualifying families have access to a wide array of professionals, including case management and an experienced parent specialist. Anyone, including family members, can refer a child for a free developmental evaluation, with eligibility based on the following criteria:

- Displays a 50 percent delay in any area of development (cognition, communication, motor, self-help, or social emotional skills).
- Displays a 25 percent delay or more in any two areas of development.
- Has a diagnosis or disability that impairs typical development.
- Has a significant health condition that puts them at high risk for developmental delays.
- Has vision or hearing loss.

ND Early Intervention also includes a screening program called Right Track. This program offers free developmental screenings and parent information. To make a referral or to learn more, call the Disability Services Division at 800.755.8529 or visit www.nd.gov/dhs/services/disabilities.



Interventions for Autism Spectrum Disorders (ASD)

There are a number of behavioral and educational interventions currently available for individuals with ASD. Not every treatment may be appropriate for every child.

One way to determine if a particular treatment may be effective is to evaluate the research. The National Standards Report from the National Autism Center (NAC) utilizes a Strength of Evidence classification system to demonstrate the NAC's confidence about the efficacy of a specific intervention. Ratings reflect the quality, quantity and consistency of the research findings.

The 2009 National Standards Report can be found online at: www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf.

It is also important that you speak with your child's physician to discuss the different therapy options.



Evidence-Based Practices

Type of Intervention	Ages	Diagnostic Classification Autistic Disorder (AD); Aspergers Syndrome (AS); Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS)
Antecedent Package	3-18	AD
Behavioral Package	0-21	AD; PDD-NOS
Comprehensive Behavioral Treatment for Young Children	0-9	AD; PDD-NOS
Joint Attention Intervention	0-5	AD; PDD-NOS
Modeling	3-18	AD; AS; PDD-NOS
Naturalistic Teaching Strategies	0-9	AD; PDD-NOS
Peer Training Package	3-14	AD; PDD-NOS
Pivotal Response Treatment	3-9	AD
Schedules	3-14	AD
Self-Management	3-18	AD
Story-Based Intervention Package	6-14	AD; AS

Useful Websites

Applied Behavior Analysis (ABA)

www.behavior.org/autism www.abaresources.com www.aba4autism.com

Different types of ABA include (but are not limited to):

- Discrete Trial Training (DTT)
 www.polyxo.com/discretetrial
 www.dtttrainer.com
- Pivotal Response Training (PRT)
 www.autismspeaks.org/treatment/prt.php
 www.dbpeds.org/articles/detail.cfm?TextID=229
- Early Intensive Behavioral Intervention (EIBI) www.asatonline.org/intervention/procedures/early.htm www.bcbs.com/blueresources/tec/vols/23/23 09.pdf
- Verbal Behavior Intervention (VBI) www.teenagerswithautism.com www.verbalbehaviorapproach.com/

Occupational Therapy

 $www.webmd.com/brain/autism/benefits-of-occupational-therapy-for-autism\ www.aota.org/Consumers/WhatisOT/RDP/Facts/38517.aspx$

Speech Therapy

www.webmd.com/brain/autism/benefits-speech-therapy-autism www.asha.org/uploadedFiles/public/speech/disorders/TESAutisticSpectrum.pdf

Social StoriesTM

www.polyxo.com/socialstories www.thegraycenter.org www.sandbox-learning.com

Family Support Services

Care Coordination for Children with Special Health-Care Needs

Meeting the complex health needs of children and their families often requires special assistance in the form of care coordination. The Care Coordination Program through Children's Special Health Services (CSHS) helps eligible families access services and resources in their community and, when needed, across multiple service delivery settings. For more information, refer to the following websites:

- Medical Home www.medicalhomeinfo.org
- **Grand Forks Public Health**http://grandforksgov.com/gfgov/Health.nsf/Pages/Care+Coordination
- County Social Services www.nd.gov/dhs/locations/countysocialserv/index.html
- North Dakota Integrated Services www.ndcpd.org/ndis/

<u>Child Care Assistance Program</u> provides financial assistance to low-income families for child care costs.

North Dakota Department of Human Services 600 East Boulevard, Dept. 325, Bismarck, ND 58505 701.328.2332

Public Assistance Toll-Free Number: 800.755.2716 www.nd.gov/dhs/services/financialhelp/childcare.html

<u>Child Care Resource and Referral</u> provides assistance locating child care and other related services.

Bismarck – 701.223.1510 or 888.223.1510 Fargo – 218.299.7026 or 800.941.7003 Grand Forks – 701.772.3435 or 888.778.3435 Minot – 701.838.7800 or 800.450.7801 Jamestown – 701.252.0350 or 888.767.0350 www.ndchildcare.org



<u>Disability Services Division</u> provides services to North Dakota citizens of all ages with developmental disabilities. Call your regional Human Service Center or the Disability Services Division at 800.755.8529. www.nd.gov/dhs/services/disabilities

- Family Care Option provides respite care to families through short-term foster home placement.
- Family Subsidy Program provides financial help needed by the family to care for the child at home.
- **Infant Development Program** provides intervention services in the home or other natural settings by trained professionals to promote optimum development of children from birth to age 2.
- **Respite Care Program** provides services of a specially trained caregiver to provide the family with occasional relief from the stress of providing care.
- **Right Track** provides child development consultations for children from birth to age 3. For more information, call 800.755.8529.
- **Supportive Home Care** assists with and teaches parents about the special care the child needs.
- Experienced Parent Program provides support services to parents with children enrolled in early intervention.

<u>Family Voices of ND</u> is a health-care information and education center, which includes the Parent to Parent Project, a program that offers emotional support to families. Call 701.493.2634 or 888.522.9654 www.fvnd.org

FamNet supports collaboration between family support organizations to improve health outcomes for families of children, youth and adults with special health-care needs and/or disabilities. Partner agencies have come together to develop a portal to help guide others to agencies that will best help meet family needs. www.ndcpd.org/famnet

<u>Federation of Families</u> provides support and advocacy for children's mental health. Call 701.250.1795 or 800.492.4951 www.fcsn.org

Legal Services of North Dakota

P.O. Box 1893 Bismarck, ND 58502-1893 701.222.2110 or 800.634.5263

National Alliance on Mental Illness North Dakota

P.O. Box 3215 Minot, ND 58702-3215 701.857.3345 **National Dissemination Center for Children with Disabilities (NICHCY)** is

an information clearinghouse that provides free information about disabilities and disability-related issues. For more information, call 800.695.0285.

www.nichcy.org

Pathfinder Family Center, Inc.

Statewide Parent Training and Information 1600 2nd Ave. S.W., Ste.19 Minot, ND 58701 701.837.7500 or 800.245.5840 www.pathfinder-nd.org

Protection and Advocacy Project

400 E. Broadway, Ste. 409 Bismarck, ND 58501 701.328.2950 or 800.472.2670

Fax: 701.328.3934 TTY: 800.366.6888

www.ndpanda.org

Regional Resource Centers for Independent Living provides services that help young people with disabilities with transition from home and school to the work place and independent living. www.freedomrc.org/links.html

Dakota Center for Independent Living

311 East Broadway Bismarck, ND 58501 701.222.3636 or 800.489.5013

Freedom Resource Center

2701 9th Ave. S., Ste. H Fargo, ND 58103 701.478.0459 or 800.450.0459

Options Interstate Resource Center

318 3rd St. N.W. East Grand Forks, MN 56721 218.773.6100 or 800.726.3692

Independence, Inc.

300 3rd Ave. S.W., Ste. F Minot, ND 58701 701.839.4724 or 800.377.5114

Ronald McDonald House Charities provides a temporary residence near the medical facility where family members can sleep, eat, relax and find support from other families in similar situations. In return, families are asked to make a donation, but if that isn't possible, the stay is free.

Bismarck

609 N. 7th St. Bismarck, ND 58501 701.258.5076 www.rmhcbismarck.com

Fargo

1330 18th Ave. S. Fargo, ND 58103 701.232.3980 www.rmhcfargo.org

Information and Referral Services

Children's Special Health Services (CSHS)

North Dakota Department of Health State Capitol – Judicial Wing 600 East Boulevard Ave., Dept. 301 Bismarck, ND 58505-0200

701.328.2436 Toll-free: 800.755.2714 Relay TDD: 701.328.3975

E-mail: dohcshsadm@nd.gov

Children's Special Health Services is a program that helps children with special health-care needs and their families. Individuals are encouraged to call CSHS for free health-care information. CSHS can also help with referrals to health-care providers and special programs for children with chronic health conditions.

www.ndhealth.gov/cshs

<u>County Social Services</u> administers economic assistance and social service programs. To inquire about assistance, please check your local phone book under county government. <u>www.nd.gov/dhs/locations/countysocialserv</u>

Pediatricians and Family Doctors

Lists of primary care doctors who practice in North Dakota are available upon request. All children benefit from a medical home. A medical home is not a building, but rather an approach to providing comprehensive medical care. In a medical home, a physician or other medical provider works in partnership with the family/patient to assure that the medical and non-medical needs of the child/youth are met. Through this partnership, the medical provider can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

Public Health

Local public health units provide a variety of services such as immunizations, home visits, high-risk infant follow-up, general child health services, community wellness programs, and school health screenings. www.ndhealth.gov/localhd

Organizations

Autism Society of North Dakota (AutismND)

The purpose of AutismND is to increase public awareness; advocate for appropriate services; provide information regarding treatment, education, research and advocacy. Call 800.328.8476 (800.3AUTISM). www.autism-society.org or www.autismnd.org

<u>Autism Speaks</u> provides funding for research into the causes, prevention, treatments and a cure for autism; to increase awareness of autism spectrum disorders. Call 888.288.4762 (888.AUTISM2) www.autismspeaks.org

National Autism Association of Central North Dakota

The purpose is to create direct-assistance programs for families affected by autism; to provide autism research funding, ongoing advocacy, support and education. Call 877.622.2884 (877.NAA.AUTISM). www.nationalautismassociation.org

North Dakota Autism Center, Inc. (NDAC)

NDAC offers The AuSome Kids Day Program and AuSome Kids 1:1 Early Intervention Program. The Day Program is a center-based child care program for preschool and school-age children with autism spectrum disorders and similar disabilities. The Early Intervention Program is a personalized program for children with autism spectrum disorders. The NDAC staff uses positive reinforcement, prompting and social stories to assist the development of communication skills, appropriate play skills, social interaction skills, academic skills, and self-help skills as well as the reduction of challenging behaviors.

4733 Amber Valley Parkway, Ste. 200 Fargo, ND 58104 701.277.8844

www.ndautismcenter.org

Talk About Curing Autism (TACA)

TACA holds monthly meetings that feature educational speakers on important topics and allow family members to connect with one another and stay on top of the latest information in the autism world. Each TACA group maintains a resource library of the latest autism books and DVDs/CDs that can be checked out by members at no charge. www.talkaboutcuringautism.org

Easter Seals Goodwill ND, Inc.

Services include, but are not limited to respite or relief care; personal care services and domestic homemaker services; equipment loan; advocacy for individuals with disabilities; and information and referral.

Dickinson

2125 Sims St. P.O. Box 361 Dickinson, ND 58602-0361 866.895.1587

Fargo

15 South 21st, Ste. 105 Fargo, ND 58103-1435 866.895.1588

Grand Forks

3651 S. Washington St. Grand Forks, ND 58201-7201 866.876.1015

Jamestown

203 Business Loop West P.O. Box 756 Jamestown, ND 58402-0756 866.897.6004

Mandan

211 Collins Ave. P.O. Box 1206 Mandan, ND 58554-1206 701.663.6828 Toll-free: 800.247.0698 www.esgwnd.easterseals.com

Minot

800 12th Ave. S.W. Minot, ND 58701-9114 866.895.1589

North Dakota Interagency Project for Assistive Technology (IPAT)

Services include information and referral, training, technical assistance to systems and individuals, equipment loan library, outreach activities, a link between state and private entities, resource development, alternative loan program, and dissemination of assistive technology materials based on consumer input. www.ndipat.org

Fargo

3509 Interstate Boulevard Fargo, ND 58103 701.365.4728 or 800.895.4728

Bismarck

400 East Broadway, Ste. 501 Bismarck, ND 58501 701.355.4615 or 888.540.4728

North Dakota Center for Persons with Disabilities

Minot State University 500 University Ave. West Minot, ND 58707 800.233.1737 www.ndcpd.org

North Dakota Chapter of the March of Dimes Birth Defects Foundation

1330 Page Drive, Ste. 102 Fargo, ND 58103 701.235.5530

www.marchofdimes.com/northdakota

Shriners Hospitals for Children-Twin Cities provides care for children (age 17 and younger) with orthopedic problems and burns. Some of the common orthopedic problems treated at Shriners include scoliosis, osteogenesis imperfecta, orthopedic problems of cerebral palsy, hand problems, back problems, limb deficiencies and growth problems, orthopedic problems of spina bifida with myelodysplasia, club foot and dislocated hip, leg-length discrepancies, orthopedic problems resulting from neuromuscular disorders, legg-perthes disease, rickets, and juvenile rheumatoid arthritis. Evaluation clinics are offered throughout North Dakota. For more information, call Shriners Hospital for Children –Twin Cities at 888.293.2832 or the patient referral line at 800.237.5055. www.shrinershq.org

The Arc of North Dakota

The Arc is a member and volunteer-driven nonprofit organization that offers advocacy, education and family support to children and adults with intellectual disabilities and related developmental disabilities and their families.

Bismarck

The Arc of Bismarck 1211 Park Ave. Bismarck, ND 58504 701.222.1854 www.thearcofbismarck.org

Dickinson

The Arc of Dickinson P.O. Box 1421 Dickinson, ND 58601 701.483.4272

Fargo

The Arc of Cass County 255 North University Drive Fargo, ND 58102 701.293.8191 www.arccassnd.com

Grand Forks

The Arc, Upper Valley 2500 Demers Ave P.O. Box 12420 Grand Forks, ND 58208-2420 701.772.6191 www.thearcuppervalley.com

Valley City

The Arc of Barnes County 700 11th St. N.W. #135 Valley City, ND 58072 701.845.5845

PARENT SUPPORT

ADVOCATING

Libraries

North Dakota Center for Persons with Disabilities Autism Links

www.ndcpd.org/alinks

North Dakota State Library

701.328.4622 or toll-free at 800.472.2104 www.library.nd.gov

Children's Special Health Services Resource Library

Toll-free: 800.755.2714

www.ndhealth.gov/cshs/docs/cshs-resource-catalog.pdf

Pathfinder Services of North Dakota Library

Toll-free: 800.245.5840

www.pathfinder-nd.org/lib.html

Prevention Resource Center

Topics in mental health, substance abuse, aging and disabilities Toll-free at 800.642.6744 http://odinlibrary.org/ndspr.html



Education

Head Start

Head Start and Early Head Start are comprehensive child development programs. Regular Head Start programs are for children ages 3 and 4. Some communities offer a program specifically for families with children younger than 3 and pregnant women. A variety of services are provided through Head Start programs including health, education, parent involvement, family literacy, social services and services for children with disabilities. Call the Head Start State Collaboration office at 800.472.2622 or your local Head Start program.

www.nd.gov/dhs/services/childfamily/headstart

School Nursing

The purpose of school nursing is to support the educational process by contributing positively and significantly to the health, health attitudes and health behaviors of today's children, and consequently, tomorrow's adults. Contact the Department of Health at 701.328.2493 or your local school nurse. www.ndhealth.gov/school-nursing

Special Education

It is important to locate and identify children who are in need of special services as early as possible. Screening and assessment opportunities offered at school help identify possible areas of difficulty that could interfere with a child's learning or academic performance. Some children with disabilities may require special education services to address their unique educational needs. Contact the Department of Public Instruction at 701.328.2260 or your local special education unit. www.dpi.state.nd.us



Health-Care Coverage Options

Medical Coverage

<u>Medicaid</u> provides comprehensive medical, dental and vision coverage to North Dakota children and adults through a variety of coverage programs and waivers. They include:



- Autism Spectrum Disorder Waiver provides services for young children from birth to age 5 who have a diagnosis of an autism spectrum disorder. The waiver will give families access to an evaluation team that can validate their child's diagnosis and serve as a resource for the family's local service providers. Other waiver services include Developmental Disabilities Program Management, parent training and support (Intervention Coordination), and In-Home supports (additional care giving to help with day-to-day activities and respite). The waiver also provides financial help with the cost of equipment, supplies and environmental modifications. Apply by contacting the Developmental Disabilities Unit at one of the regional human service centers. Contact information is online at www.nd.gov/dhs/locations/regionalhsc.
- Children with Disabilities Medicaid Coverage allows qualifying children with disabilities to buy into Medicaid. The program provides comprehensive coverage through Medicaid, including dental and mental health coverage, in return for a premium. Apply at your local county social service office.
- Children and Family Coverage provides coverage to children younger than 21, to pregnant women, and to adult caretakers of deprived children. Most receive full coverage; however, some with higher income may be required to pay for a portion of their care. Apply at your local county social service office.
- Children's Hospice Services Waiver provides support to families so they can care for their children (from birth through age 21) in their homes as long as possible avoiding lengthy stays and delaying or avoiding institutional care. The child must have a diagnosis and not be expected to live longer than one year. The program also allows families to access treatments that focus on curative and comfort care for their children. To apply call 701.328.4630.
- Children with Medically Fragile Needs Medicaid Waiver is designed to assist qualifying medically fragile children between ages 3 and 18. The child needs to be living at home, be Medicaid eligible, be able to meet Level of Care criteria for a nursing home and meet criteria based on the Level of Need. To apply call 701.328.4630.

- Home and Community-Based Services Waiver provides alternative services for individuals with disabilities who are at least 18 years of age and individuals older than 65 years of age who are eligible for the Medicaid Program and have medical needs that would qualify them to enter a nursing facility. The waiver allows North Dakota to pay for alternative services needed for these individuals to remain in their own homes or community settings. Recipients may be required to pay for a portion of their care based on their income. Apply at your local county social service office.
- Intellectual Disabilities/Developmental Disabilities Waiver assists eligible individuals with intellectual disabilities and developmental disabilities to remain living at home and in the community. This waiver serves individuals through the lifespan (both children and adults). Services offered under the waiver include Developmental Disabilities Program Management; Infant Development (for children from birth to age 3); In-Home Supports; Assistance with transportation costs, equipment, supplies, and environmental modifications; and Adult services such as day services, job coaching, and residential services. Apply by contacting the Developmental Disabilities Unit at one of the regional human service centers. Contact information is online at www.nd.gov/dhs/locations/regionalhsc/.
- Workers with Disabilities Medicaid Coverage allows some individuals with
 disabilities who want to work, or who are already working and who want to
 increase their earnings, to do so without fear of losing their Medicaid coverage. It
 allows qualifying individuals to buy into Medicaid. The program provides comprehensive coverage through Medicaid, including dental and mental health coverage, in return for a premium. Apply at your local county social service office.

<u>Healthy Steps</u> is a benefit program for eligible North Dakota children to age 19 who do not have a source of health-care coverage. The program offers comprehensive medical, dental and vision coverage. Call 877.KIDS.NOW or 877.543.7669.

<u>Caring for Children</u> is a benefit program for eligible North Dakota children to age 19 who do not have another source of health-care coverage. The program offers primary medical and dental care, as well as mental health and chemical dependency treatment. Call 800.342.4718.

<u>Children's Special Health Services Specialty Care Diagnostic and Treatment</u>

<u>Program</u> helps families pay for medical services to diagnose and treat children with eligible medical conditions from birth to age 21. Call 800.755.2714

<u>Comprehensive Health Association of North Dakota (CHAND)</u> provides comprehensive health insurance to residents of North Dakota who have been denied health insurance or are considered high risk. Call 800.737.0016.

<u>Student Health Plans</u> are available for purchase by students who don't have health insurance through a parent's health insurance policy or who have limited coverage due to network service areas. Student plans are sold by an insurer that has contracted with a college to offer coverage to its students. In general, these plans have more limited benefits and more exclusions than traditional health insurance plans. Contact an insurance agent to inquire about student health plans.

Vision Coverage

<u>InfantSEE®</u> is a public health program designed to ensure early detection of eye conditions in babies. Member optometrists provide a comprehensive eye and vision assessment for infants within the first year of life regardless of a family's income or access to insurance coverage. Call 888.396.3937. www.infantsee.org

<u>New Eyes for the Needy</u> purchases new prescription eyeglasses through a voucher program for children and adults in the U.S. who cannot afford glasses on their own. www.neweyesfortheneedy.org.

<u>Vision USA</u> provides basic eye health and vision care services free of charge to uninsured, low-income people and their families. Call 701.258.6766.

www.aoa.org/visionusa.xml

<u>VSP Sight for Students</u> is a charity that provides free vision exams and glasses to low-income, uninsured children. Call 888.290.4964.



Prescription Coverage

<u>Prescription Connection for North Dakota</u> is a program of the North Dakota Insurance Department that connects kids and families with free and discounted prescription drugs direct from the pharmaceutical manufacturer. Call 888.575.6611. www.rxconnectnd.org

ND Prescription Drug Repository Program collects and distributes donated medications from hospitals, hospices and other facilities so that pharmacies and physicians can dispense them to those who struggle paying for prescriptions regardless of insurance coverage. The medications and supplies are unopened and secure but cannot be resold to patients. www.nodakpharmacy.com

<u>NeedyMeds</u> offers a database of medications that can be obtained free or at low cost by uninsured, low-income patients, usually through manufacturer programs. <u>www.needymeds.org</u>

<u>Partnership for Prescription Assistance</u> offers a single point of access to more than 475 public and private patient assistance programs. It is funded by pharmaceutical companies. Call 888.477.2669. www.pparx.org

RX Assist provides consumer information, resources, news and a directory of patient assistance programs that offer affordable or free medications. Call 401.729.3284. www.rxassist.org

Dental Coverage

<u>Safety Net Dental Clinics</u> are programs that usually see patients who do not have other access to dental care. The patients typically are covered by Medicaid or the clinic offers sliding fee schedules or reduced fees.

- **Bridging the Dental Gap** is a nonprofit community dental clinic serving low-income and uninsured individuals in the Bismarck-Mandan area. Call 701.221.0158.
- Family Healthcare Center Dental Clinic is a federally qualified community health center serving low-income and uninsured individuals within the Fargo Red River Valley Region. Call 701.271.3332.
- Northland Community Health Center Dental Clinic is part of a federally qualified community health center serving low-income, uninsured and insured individuals of all ages in central North Dakota. Call 701.448.9111.
- Red River Valley Dental Access Project serves low-income, uninsured and Medicaid-eligible individuals who have urgent dental pain and do not have access to a dentist in Fargo-Moorhead. Call 701.364.5364.
- Valley Community Health Center Dental Clinic is a federally qualified health center serving low-income, uninsured and insured individuals of all ages in the Northern Red River Valley. Call 701.757.2100.

North Dakota Donated Dental Services is a network of volunteer dentists who provide dental care to the state's most vulnerable people: disabled, elderly or medically compromised individuals who cannot afford necessary treatment nor get public aid. Call 866.572.9390.

<u>Jerene's Wish</u> is a program that provides orthodontic treatment at a minimal cost to eligible children. For more information, call Warford Orthodontics at 701.255.1311 or e-mail info@warfordorthodontics.com.

<u>Smiles Change Lives</u> promotes and provides access to essential orthodontic treatment for children from low-income families. 888.900.3554. <u>www.smileschangelives.org</u>

<u>The Ronald McDonald Care Mobile</u> is a mobile dental clinic on wheels that delivers urgently needed dental care to underserved children from birth through age 21 in their own neighborhoods in the western half of North Dakota. The Ronald McDonald Care Mobile treats children who do not have a regular dentist and who have not seen a dentist within the past two years. www.rmhcbismarck.org/caremobile/

Health-Care Programs

Bridge to Benefits is a multi-state project sponsored by the Children's Defense Fund—Midwest Region focused on improving the well-being of families and individuals by linking them to public work support programs and tax credits. For more information, call 701.400.1827 or visit nd.bridgetobenefits.org.

<u>Shriners Hospitals for Children</u> provide no-cost medical care to children with orthopedic problems, spinal cord injuries or burns. Call 800.237.5055.

<u>Community Health Centers (CHC)</u> serve all patients regardless of their ability to pay for services. CHCs are located in Beulah, Center, Fargo, Grand Forks, Larimore, McClusky, Northwood, Rolette, Rolla, Towner and Turtle Lake. Call 701.221.9824 for specific site contact information.

North Dakota Association for the Disabled (NDAD) may provide fund raising or some financial assistance for individuals with disabilities. Call 800.532.6323.

<u>United Health Care Children's Foundation</u> supports the concept of facilitating access to health-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by an available commercial health benefit plan. The Foundation provides financial assistance toward the family's share of the cost of medical services. www.uhccf.org

<u>Indian Health Service (IHS)</u> provides health services to American Indians and Alaskan Natives who belong to federally recognized tribes. The IHS administers health services through IHS facilities, through tribally-operated facilities and by contracting for health services. <u>www.ihs.gov</u>

<u>Service Organizations</u> such as the Elks, Kiwanis, Sertoma, Lions and Quota may offer assistance with medical-related expenses. Check the local phone book for contact numbers.

^{*}Please note, this is not an all-inclusive list of health-care coverage options.

Military Resources

Medical

Tricare 888.874.9378 www.tricare.mil

Exceptional Family Members Program

Minot Air Force Base: 701.723.5720 or 701.723.5044

Grand Forks Air Force Base: 701.747.6437

Websites

www.Acttodayformilitaryfamilies.org

www.Militaryhomefront.mil



Statewide Tribal Programs

Fort Berthold Indian Reservation - Three Affiliated Tribes	
www.mhanation.com/main/main.html	
Ebowoods Memorial Health	701.627.4701
MinneTohe Health Center	701.627.4701
 Community Health Representative 	
New Town	701.627.3653
Mandaree	701.759.3441
Parshall	701.862.3872
Twin Buttes	701.938.4574
White Shield	701.743.4178
Standing Rock Indian Reservation	
www.standingrock.org	
Public Health Service Hospital	701.854.3831
• IHS Clinics - Cannonball, N.D.	701.854.3453
 Community Health Representative 	
Fort Yates	701.854.3856
Cannonball	701.854.9926
Tribal Health	701.854.7206
Early Childhood Tracking	701.854.3678
Fort Totten Indian Reservation - Spirit Lake Nation	
www.spiritlakenation.com	
Indian Health Service Clinic	701.766.1600
Maternal Child Health	701.766.1251
Tribal Health	701.766.4236
Community Health Representative	701.766.4238
• Early Childhood Tracking 701.766.1232	
Trenton Indian Service Area	
www.ndhealth.gov/localhd/TISA	
Trenton Community Clinic	701.774.0461
Community Health Representative Coordinator	701.774.0303
• Tribal Health	701.774.0461
Turtle Mountain Indian Reservation	
www.tmbci.net	
• Quentin Burdick Health Facility701.477.6111	
Community Health Representative	701.477.5696
Tribal Health	701.477.6120

Websites

Condition-Specific Websites:

Anne Carlsen Center www.annecenter.org

Autism 101 for EMS Providers

www.papremisealert.com

Autism Speaks

www.autismspeaks.org

Autism Web

www.autismweb.com

Autism Society of America

www.autism-society.org

Autism Society of North Dakota

www.autismnd.org

Autism Research Institute

www.autism.com

Autism Today

www.autismtoday.com

Autism Link

www.autismlink.com

C.A.R.D.

www.centerforautism.com

Changing Behavior

www.youcangrowtoday.com

First Signs

www.firstsigns.org

National Autism Association

www.nationalautismassociation.org

North Dakota Autism Center

www.ndautismcenter.org

Red River Valley Asperger Network

www.impactgiveback.org/view nonprofits

Sound Advice on Autism

www.aap.org/audio/autism



Additional Websites for Families of Children with Special Health-Care Needs:

American Academy of Pediatric

www.aap.org

Bright Futures

www.brightfutures.org

CDC Parent Information

www.cdc.gov/parents

Dr. Greene's House Calls

www.drgreene.com

Early Intervention

www.nd.gov/dhs/services/disabilities/

earlyintervention

Family Village

www.familyvillage.wise.edu

Gillette Children's Specialty Healthcare

www.gillettechildrens.org

Healthy & Ready To Work (HRTW)

www.syntiro.org/hrtw

Institute for Child Health Policy (ICHP)

www.ichipufl.edu

Kids As Self Advocates (KASA)

www.fvkasa.org

Mayo Health Clinic

www.mayoclinic.com

Medical Home National Center

www.medicalhomeinfo.org

Medical Home Portal

www.medicalhomeportal.org

MUMS (parent support)

www.netnet.net/mums

National Organization for Rare Disorders

(NORD)

www.rarediseases.org

ParentsPlace

www.ivillage/pregnancy-parenting

Social Security Administration

www.ssa.gov

Starlight/Starbright Children's

wFoundation

www.starlight.org

University of Minnesota Children's

Amplatz Hospital

www.uofmchildernshospital.org



Notes

Comments?

Please send comments or suggested edits for this book to:

North Dakota Department of Health Division of Children's Special Health Services 600 East Boulevard Ave., Dept. 301 Bismarck, ND 58505-0200





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E-mail: dohcshsadm@ndgov www.ndhealth.gov/cshs

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